

**Editors**

E.E. van der Wall	Leiden
<i>chairman</i>	
P.A.F.M. Doevendans	Maastricht
M.J.M. Cramer	Utrecht
A.A.M. Wilde	Amsterdam
F. Zijlstra	Groningen

**Editorial Board**

F.W.H.M. Bär	Maastricht
M.J. de Boer	Zwolle
H.A. Bosker	Arnhem
A.J.M. Cleophas	Dordrecht
H.J.G.M. Crijns	Maastricht
P.J. de Feyter	Rotterdam
J.A. Gevers Leuven	Leiden
W.H. van Gilst	Groningen
R.N.W. Hauer	Utrecht
N.M. van Hemel	Utrecht
T.E.H. Hooghoudt	Nijmegen
M.C. Huige	Eindhoven
W. Jaarsma	Utrecht
J.W. Jukema	Leiden
J.L.M. Jordaens	Rotterdam
H.J. Kirkels	Utrecht
J.J. Koolen	Eindhoven
A. van der Laarse	Leiden
K.I. Lie	Amsterdam
H.R. Michels	Eindhoven
M.G. Niemeyer	Groningen
L. Noyez	Nijmegen
T. Op 't Hof	Utrecht
N.H.J. Pijls	Eindhoven
J.H.C. Reiber	Leiden
W.J. Remme	Rotterdam
A.C. van Rossum	Amsterdam
J.J. Schipperheyn	Leiden
P.W.J.C. Serruys	Rotterdam
M.L. Simoons	Rotterdam
J.L.R.M. Smeets	Maastricht
D.J. van Veldhuisen	Groningen
F.W.A. Verheugt	Nijmegen
C.A. Visser	Amsterdam
H.W. Vliegen	Leiden
T. van der Werf	Nijmegen
E.F.D. Wever	Nieuwegein
R.J. de Winter	Amsterdam
P.A. van Zwieten	Amsterdam
V. Manger Cats	NHS
A.J.A.H. Scholte	Junior Chamber
N.M. Panhuyzen-Goedkoop	CVOI

## Quality of life in adults with congenital heart disease

The number of adults with congenital heart disease is growing as a result of advances in medical and surgical treatment. Many patients with corrected or palliated congenital heart disease will suffer from medical complications. Mortality and morbidity are the conventional measures for the effects of treatment and prevention in medicine. However in chronic disease, such as grown-up congenital heart disease, health-related quality of life and psychosocial issues are of major importance. In the methodological literature, consensus about the definition of health-related quality of life is growing. Health-related quality of life is considered to be a multidimensional construct, including domains of physical, social, cognitive and emotional functioning of the patient. Literature invariably shows considerable disagreement between patients and proxies (such as the parent, physician, nurse or others) in their ratings of the patient's health-related quality of life. Therefore, it is commonly proposed that the perception of the patient is crucial to the concept of health-related quality of life. In addition, several authors have suggested a second level of subjectivity to the concept of health-related quality of life, i.e. the value that the patient assigns to the perception of functioning. In fact, we are not only interested in the patient's perception of his ability to climb the stairs (subjective health status), but we also want to know his personal feelings about that ability or disability (health-related quality of life).

Based on this concept, the Leiden Centre for Child Health and Paediatrics developed a dedicated questionnaire called the TNO-AZL Adult Quality of Life questionnaire (TAAQOL).<sup>1</sup>

In November 2002, Dr. Mascha Kamphuis successfully defended her thesis: 'Quality of life in adults with congenital heart disease.'<sup>2</sup> In this thesis, Dr. Kamphuis reported on the investigations, using amongst others the TAAQOL questionnaire, in patients with previously operated complex congenital heart disease, patients with mild congenital heart disease and reference groups.

From a meta analysis on quality of life in adults it was concluded that health-related quality of life in research with congenital heart disease patients is seldom defined clearly and measures often aim at different targets. Therefore, studies should be compared with great caution. Health-related quality of life outcome is surprisingly positive in most studies that measured congenital heart disease patients' own perceptions. This might be explained by coping mechanisms.

In patients with previously operated complex congenital heart disease, investigated with the TAAQOL, the relation between these measures and physical indices were determined.<sup>3</sup> The health-related quality of life of the patients was significantly worse than that of the general population in the domains gross motor functioning and vitality. Correlations between health-related quality of life and physical indices were poor. This result indicates that these patients need specific attention for their physical quality of life. Objectively determined physical indices are only weakly related to health-related quality of life. Therefore, when evaluating quality of life, dedicated questionnaires such as the TAAQOL should be used.

In patients with haemodynamically insignificant congenital heart disease, of which only a minority were still under cardiac supervision, the health-related quality of life did not differ from that in the general population. Nevertheless, patients experienced unnecessary difficulties with

**Management, editorial office,  
advertising sales and administration**

Mediselect bv  
PO Box 63, 3830 AB Leusden,  
The Netherlands  
Tel.: +31-33-422 99 00  
Fax: +31-33-422 99 22  
E-mail: info@mediselect.nl

ISSN 0929-7456

Netherlands Heart Journal is published eleven times a year by Mediselect, the Netherlands Heart Foundation and the Netherlands Society of Cardiology. Netherlands Heart Journal is the official journal of the Netherlands Society of Cardiology.

Netherlands Heart Journal is made available to cardiologists, cardiologists in training, cardiopulmonary surgeons, cardiopulmonary surgeons in training, internists and paediatric cardiologists.

The Editorial Board is independent. The opinions expressed by the Editorial Board and the authors of articles are not necessarily those of the Netherlands Heart Foundation, the Netherlands Society of Cardiology or the Publisher. The content of the Nieuwsbrief and the CVOI section does not fall under the responsibility of the Chief Editors.

Circulation: 2900 copies.

**Subscriptions**

Annual rates for companies and institutions € 98; for personal subscribers € 86. Price per issue € 12, excl. postage costs. All prices include value added tax (VAT). Other rates on request. Subscriptions can commence at any moment. The first subscription period runs until the end of the calendar year; the subscription is subsequently renewed automatically for a further year. Cancellations should be made, in writing, to the Publisher at least two months before the start of the new subscription period.

©2003 Mediselect

All Rights Reserved. No part of this publication may be reproduced, stored in retrieval, or transmitted in any form or by any other means, electronic, mechanical, photocopying, recording or otherwise, without prior permission, in writing, of the Publisher.

The Editorial Board and Publisher will not be responsible for the content of the articles published under an author's name or of the advertisements.

Mediselect publishes Netherlands Heart Journal, Nederlands Tijdschrift voor Heelkunde, Tijdschrift voor Huisartsgeneeskunde, Praktijkmanagement, Apotheekmanagement, online, Lijfblad, Nederlands Tijdschrift voor Calcium- en Botstofwisseling, Tijdschrift voor Cardiologie (B), Journal de Cardiologie (B), Clinical Cases (Int) and The European Journal of General Practice (Int).

Mediselect also produces patient information folders, organises congresses and symposia, and provides marketing-supporting activities.



mediselect bv

their choices of sport, education, or obtaining insurance cover. After clinical re-evaluation, diagnosis and antibiotic regimens had to be changed in 11% of these patients, for instance as a result of a resolved ventricular septal defect. It was therefore concluded that patients with mild congenital heart lesions consider themselves to be in good health. However, to fine tune diagnosis and update patient information, at least a cardiological assessment should be done at the age of 16 to 18 years. In this way, patients might be protected from unnecessary difficulties, such as restrictions for sport or the charging of unjustifiably high rates for insurance.

A minority of patients with minor disease and a majority of those with complex congenital heart disease report difficulties in daily life. A substantial number of these patients feel that they have an inadequate level of knowledge about their disease.

Paid employment is important in daily life, not only in terms of earnings and social status, but it is also valued for its social support and social distraction. Although various studies have shown that the majority of patients with congenital heart disease are able to work, it is unclear whether patients experience handicaps and which factors are related to reduced job participation. Such information could contribute to improvements vocational counselling and employment prospects of patients with congenital heart disease. Kamphuis et al.<sup>4</sup> showed that patients with complex congenital heart disease have reduced job participation, as compared with patients with mild congenital heart disease and the general population. Many receive disablement benefit, or experience career problems or job handicaps for mobility.

Multiple logistic regression showed that the severity of disease and level of education were significantly and independently related to job participation. Career counselling focusing on physical abilities and level of education may help to prevent or reduce these job-related problems.

According to this thesis, the following recommendations for clinical practice were proposed:

- Since the appreciation of functioning differs from functioning per se, implementation of quality-of-life questionnaires at medical consultations should be considered to facilitate treatment decisions and for increasing satisfaction with consultation and patient compliance.
- Specifically for patients with mild congenital heart disease, knowledge about the cause and consequences of their cardiac defect is experienced as insufficient. Therefore, more attention is needed for this lack of knowledge.
- For patients with minor congenital heart disease, a routine consultation is recommended at the age of 16 to 18 years. This consultation should be used to confirm the diagnosis and need for antibiotic prophylaxis, and to discuss daily life issues and to try to prevent problems in later life, such as restrictions in sport, education and insurance.
- Career counselling should be focused on the patient's physical abilities, to prevent or reduce unemployment, career problems and handicaps. In addition, the child should be advised to follow the highest possible education. ■

*Dr. H.W. Vliegen, cardiologist.  
Leiden University Medical Centre, Leiden.*

**References**

- 1 Fekkes M, Kamphuis RP, Ottenkamp J, Verrips E, Vogels T, Kamphuis M, et al. Health related quality of life in young adults with minor congenital heart disease. *Psychol Health* 2001;16:239-51.
- 2 M. Kamphuis. Quality of life in adults with congenital heart disease. Thesis. University of Leiden, 2002.
- 3 Kamphuis M, Ottenkamp J, Vliegen HW, Vogels TG, Zwinderman AH, Kamphuis RP, et al. Health-related quality of life and health status in adult survivors with previously operated complex congenital heart disease. *Heart* 2002;87:356-62.
- 4 Kamphuis M, Vogels TG, Ottenkamp J, Wall EE van der, Verloove-Vanhorick SP, Vliegen HW. Employment in adults with congenital heart disease. *Arch Pediatr Adolesc Med* 2002;156:1143-8.